

astriid

Making employment work for people with long term conditions:

Evidence from the frontline.

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Foreword: The Astriid story

By Steve Shutts, Former CEO, Astriid.

Astriid was founded by my brother, David Shutts OBE, following his cancer diagnosis in 2017. His own lived experience, struggling to find meaningful work whilst battling with his illness left him feeling valueless at a time when he needed all his mental strength. Around one in five of the UK population is disabled and approximately one third of those disabled people of working age has an energy limiting condition. Since COVID-19 and the rise of long COVID, this number is increasing each month.

This enormous community of people, that we call the invisible talent pool, recognise that the value of work is far more than the wages paid. Employment provides routine, a sense of normality, challenges and rewards, and when approached correctly can also facilitate a greater sense of well-being.

Our aim at Astriid is to connect people with long term conditions with meaningful work. We provide practical help and support tailored to the individual needs of our candidates. We help them to develop a fresh vision for their future by supporting them in CV writing, interview skills and the identification of transferable skills.

As a charity, we are constantly evolving. One of the biggest barriers that we have identified lies in a corporate knowledge gap: business leaders want to recruit diverse talent but don't have a full understanding, nor the necessary skill, to empower people with long term conditions in the workplace. Our new consultancy and training service is designed and delivered by experts within the team who manage their own health conditions. This support can help empower employers to confidently recruit, retain and develop employees with long term conditions in their workplace.

We must make employment work for people with long-term conditions. Now is the time to transform the challenge of recruiting and managing people with such conditions into an opportunity for your organisation to flourish and become an employer of choice for this skilled community. For further information and support on kickstarting your journey, get in touch with us at **consulting@astriid.org**





Executive Summary

"I have benefitted from being able to work remotely and adjust my hours. The focus is on my work itself, rather than where and when it is completed."

Introduction

Since our last report *The Invisible Talent Pool*,[1] in 2021, an extra half a million people have left employment due to long term ill health. This brings the total number of people excluded from the world of work due to illness to a record high of over 2.5 million individuals. This represents a worrying loss of talent to businesses and to our economy, but most importantly, a devastating loss of livelihood and sense of purpose to those affected by long term health conditions. An increase in post-viral, musculoskeletal and mental health conditions is believed to play a large part in this trend.

How do we enable people with long term health conditions to make their way back into employment? This is one of the great challenges facing our society today. And yet, no one seems to be asking the very people with long term conditions and disabilities this question. This is what our survey set out to do.

Astriid is a charity that connects people with long term conditions with meaningful work and is led by lived experience experts. Our mission affords us a unique vantage point from which we can uncover the barriers and identify solutions for increasing employment opportunities for those we support.

Our survey of over 400 people with long term conditions and disabilities was conducted in Spring 2023. In this report, we draw on our research evidence to present recommendations for **businesses** wanting to reach a hidden talent pool, as well as levelling up support for existing employees, and for **government** addressing twin policy challenges: the disability employment gap and the rise in health-related economic inactivity.

Our respondents had this in common: they were highly educated; three-quarters had over ten years' professional experience and perhaps most importantly, more than 9 in 10 believed they had skills to offer to employers. Most of them live with an **energy limiting condition (ELC)**, an umbrella term that captures many common musculoskeletal, neurological and respiratory diseases as well as post-viral conditions Long Covid and ME/CFS. This group numbers around 4.7 million people in the UK and is equivalent to a third of the disabled population.[2] However, knowledge about the factors that create and sustain unemployment for this large, but neglected, cohort of disabled people is currently lacking.

[1] See https://www.astriid.org/reports/astriid-report-employment-and-long-term-illness/

[2] Source: disability data tables on 'impairment of stamina, breathing, fatigue' from the Family Resources Survey 2019/2020, Department for Work and Pensions.

Barriers to employment are multifactorial

Our survey uncovered the health-related, psychosocial and structural factors that, too often, stand between individuals with ELCs and employment.

Health

Understanding the relationship between work and health is traditionally the territory of medical professionals, leaving the lived experience of disabled people out of the picture when it comes to finding solutions. Our survey was designed to capture this important piece of missing evidence. Our results highlight the core aspects of respondents' health condition(s) that limit their capacity for work. This includes not only physical fatigue but also cognitive fatigue; unpredictable fluctuation in symptoms; and the fact that, for many, pushing through fatigue makes their condition worse and increases the likelihood of leaving the workforce permanently.

This lived experience knowledge must now be factored into Human Resource managers' knowledge base for supporting people with long term conditions, as well as into government policy and planning on disability employment.

Psychosocial factors

The most common 'fear factor' identified by respondents around re-entering the workplace after developing a chronic illness was not knowing how many hours of work they could safely undertake without causing their health to deteriorate. The emotional challenges of adjusting to the onset of a chronic illness also played a part, as did a lack of confidence when it comes to identifying and advocating for their needs within the legal framework of 'reasonable adjustments' in work.

Another major barrier to work was a lack of understanding from employers and managers about the realities of long term health conditions. These barriers need to be addressed through targeted education and training for HR professionals and line managers, as well as through employer engagement by employment support services.

The availability of inclusive work

The third barrier we present is the lack of accessible jobs available within the labour market. Although the skills, passion and motivation to work among our respondents was not diminished by acquiring a long term health condition, individuals in this group have a reduced capacity for work. They must arrange their work tasks into smaller units of time, with a need to manage the pace and schedule of work to accommodate symptoms and avoid the risk of over-exertion and deterioration. Our respondents told us that the hours and location of work described on a job advertisement are a key determining factor of whether they would consider applying for the role.

Rethinking employment support services

Survey respondents indicated that they greatly value the employment support measures we provide at Astriid. Job brokering and job matching are, by far, the most highly prized aspect of our offer. Respondents overwhelmingly wanted an introduction to an employer who understands long term conditions, rather than undergoing an impersonal recruitment process with its inherent uncertainty over whether or when to reveal their health condition.

Building confidence about advocating for their adjustment needs, reframing their employment history and professional identity, re-orienting their skills, and understanding the landscape of available jobs; these were all among the types of help they sought from us. In addition, there is much more that we would like to do to respond to the demand evidenced in this survey, including health coaching once a candidate is in work, guidance on navigating the benefits system when working part-time, and peer support to build confidence.

Action from employers to increase job opportunities

Despite the popularity of our service, we must face the fact that there is only so much we can achieve by trying to shape an individual candidate to fit a standard-shaped job. We know from working with candidates that the hours and location of work are one of the important determining factors of whether they will apply for a role.

Our survey findings highlighted that flexible working solutions were the most common form of workplace adjustment needed by this population by a large margin. Part-time work, flexible hours, flexible start and finish times and working from home were each a requirement for three-quarters or more of our respondents. Most needed a combination of these types of flexibility.

Moreover, when asked what measures would help them find work, three quarters of respondents cited flexibility of hours or location of work stated in a job advert. This shows the importance of embedding flexible working into job design and recruitment, rather than only granting it as an afterthought to those who request flexible working once in a job.

Other forms of workplace adjustment are important too. For those in physical workspaces, adjustments to premises can enable essential rest breaks. Sickness absence policies should also allow for medical appointments and treatment, to ensure that employees requiring medical consultations to manage their condition are not disadvantaged because of this.

Each individual is different, but the fact remains that businesses must look to the future. With 40% of the workforce predicted to develop a long term condition

during their working lives[3], it makes strategic sense to plan for the future of work around this growing section of the workforce.

Conclusion

Our charity has unique expertise in working with disabled jobseekers, especially the significant subset living with ELCs. Our depth of knowledge and lived experience mean we can present fresh insights into the barriers to employment they face, and more importantly, advance tried-and-tested solutions. The evidence in this report addresses the urgent challenge of integrating the growing numbers of people with long-term health conditions into our economy and society. It's imperative that any solutions going forward are designed with the ELC population in mind, recognising the complex interplay between work and health for this group.

We call on the government to commission specialist employment support services for people with long term conditions that are informed by knowledge of ELCs. These services should centre on job brokering and job matching, and empowering candidates to play to their strengths. They should be developed in collaboration with lived experience experts. We equally call on employers to play their part in levelling the playing field for this significant, but invisible, talent pool. This must begin with including ELCs, alongside other long-term conditions and disabilities, in their Diversity and Inclusion strategy. Line managers must be trained to better support employees with ELCs through tailored workplace adjustments, but businesses must also go a step further: to welcome disabled talent to their workforce, they must design and incorporate part time and flexible roles into their workforce planning and job development strategy.

"I have been really fortunate when disclosing my health conditions. My employers have been really flexible, for example with phased returns, altered hours, and flexible working. My current employer sees me as a role model for balancing my needs with that of the organisation and for being clear about my boundaries."

Key findings

92% of survey respondents believe they have skills that could be of value to an employer if a suitable job were available.

98% reported that fatigue and/or limited energy from their disability limited their ability to work; **89%** from fluctuating symptoms; **87%** from 'payback' (a

[3] See https://ukhsa.blog.gov.uk/2016/09/14/understanding-the-relationship-between-health-work-and-worklessness/

deterioration in symptoms following exertion); **87%** from cognitive fatigue or 'brain fog' and **73%** from pain.

48% said they left their previous job because the working conditions caused their health to deteriorate.

49% needed to work fewer than 22.5 hours per week; only **17%** could work 35 hours or more.

66% said they were uncertain about what type or amount of work they could safely manage.

89% sought an introduction to employers who understand long term conditions.

75% sought jobs that specifically mention flexibility over working hours and location in the job advert.

84% needed to work from home.

71% sought support with managing health and wellbeing in work.

51% sought mentoring from someone with direct understanding of long term conditions.

41% said they wanted support with identifying reasonable adjustments and producing a Health Adjustment Passport.

Introduction

Astriid conducted an online survey to gather information from individuals living with long-term conditions (LTCs) or disabilities about their experiences of health and work. We opened our survey to both our registered candidates who were already signed up to receive support from Astriid, and the wider public who identified as having a long-term health condition or disability. We collected this data to help us advocate to external stakeholders on behalf of our service users, and to evidence the significant challenges faced by those with LTCs when accessing work.

Aims

The aims of this survey were to:

- Gather information from people with LTCs and disabilities about their experiences of finding work and being in work.
- To find out what kind of barriers may prevent people with LTCs from accessing work.
- To find out what kind of support would be most valuable in helping people with LTCs to access work.

Method

The design of the survey was informed by Astriid's Candidate Support team, who all have lived experience of long-term conditions themselves. Team members shared their expertise from supporting our candidates into employment, as well as their own perceptions and experiences of work and health.

The survey was open between February and April 2023. It was advertised on Astriid's website and social media platforms and via the Astriid candidate newsletter.

Respondents

The survey received 419 responses. Of these responses, 414 identified as having an energy-limiting condition (ELC) and/or identified "limited energy or fatigue" as a health-related barrier to them accessing work. As very little is known about the unique barriers to work and support needs of people with ELCs, we focussed the analysis on these 414 respondents.

What are ELCs?

Around 4.7 million people in the UK experience an impairment of stamina, breathing or fatigue which significantly restricts their day-to-day activity.[4] We refer to health conditions that cause this type of impairment as energy limiting conditions (ELCs).

[4] Disability data from Family Resources Survey, Department for Work and Pensions 2021-2022 https://www.gov.uk/government/statistics/family-resources-survey-financial-year-2021-to-2022

The ELC umbrella covers conditions where fatigue and energy impairment are **always** present, such as Long Covid, ME/CFS and chronic Lyme Disease. It also covers many more conditions where fatigue or energy impairment are **often** present. These include:

- musculoskeletal conditions like fibromyalgia, Ehlers Danlos Syndrome and rheumatoid arthritis
- respiratory conditions like COPD and cystic fibrosis
- cancer, including the treatment effects of chemotherapy.
- neurological conditions like multiple sclerosis
- gastrointestinal conditions like Crohn's Disease and irritable bowel syndrome
- heart and circulatory conditions
- endocrinological conditions
- auto-immune conditions like lupus and mast cell activation syndrome

Mental health conditions and neurodivergence can also be associated with fatigue and limited energy.

There is a wide range of disability with an ELC, depending on how an individual is affected by their condition(s). Someone with mild or moderate energy impairment may manage to hold down a job, but at the expense of any social or leisure activities outside of work. ELCs are one of many forms of invisible, or non-apparent, disability. This means the efforts individuals make to 'mask' or push through their symptoms at work are usually invisible to colleagues and managers.

Who did we hear from?

Disability identity

Of the 414 respondents who met our sampling criteria for fatigue and/or energy limiting conditions, **96%** of respondents consider themselves to be disabled.

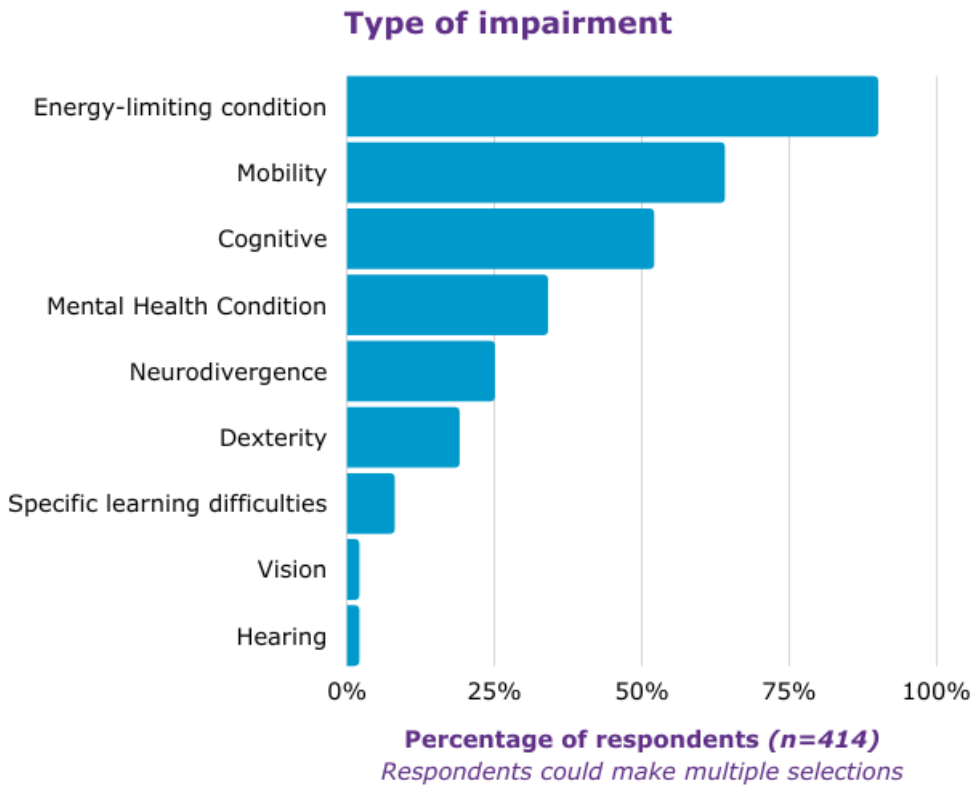


Figure 1. Graph titled 'Type of impairment'. Please see chart description below.

Figure 1. Chart Description:

Bar chart showing types of impairment reported by 414 respondents. Respondents were able to make multiple selections. Energy-limiting condition was selected by 90% respondents; mobility by 64%; cognitive by 52%; mental health conditions by 34%; neurodivergence by 19%; dexterity by 25%; specific learning difficulties by 8%; vision by 2%; hearing by 2%.

Figure 1 illustrates the multiple impairment challenges - physical, cognitive, emotional and social – reported by people with ELCs. Our survey data do not allow us to determine whether multiple impairment is due to multiple co-existing diagnoses, or due to the multiple effects of a single health condition on an individual. For example, 'mental health condition' may co-exist with, or may be a secondary effect of, living with an ELC. However, we can infer that ELCs lead to reductions in both **physical stamina**, leading to mobility restriction (64%), and **mental stamina**, leading to cognitive difficulties (52%).

This insight into multiple impairment effects challenges the traditional classification of disability types into physical, cognitive, sensory or emotional categories. Our findings demonstrate the need for a holistic understanding of the lived experience of ELCs when planning inclusion and support.

Demography

89% of respondents were women.

88% live in England.

(See Appendix for full demographic tables)

Education

70% were educated to at least Bachelor's degree level.

Work experience

In any sector

73% had over 10 years of work experience. Only 3% had under a year or none.

In desired sector

24% had no experience or under a year of experience in their desired sector. We know from our work with candidates that many of them need to change the sector they work in, due to their previous jobs being inaccessible e.g. too physically demanding or not enough opportunities to work from home.

Skills and motivation to work

92% believe they have skills that could be of value to an employer if a suitable job became available.

Barriers to employment with ELCs

We know from working directly with candidates that barriers to employment are complex and multifactorial. They typically involve interaction between health, psychosocial factors such as confidence, and structural factors connected to the way work is traditionally organised.

Illness related barriers to work

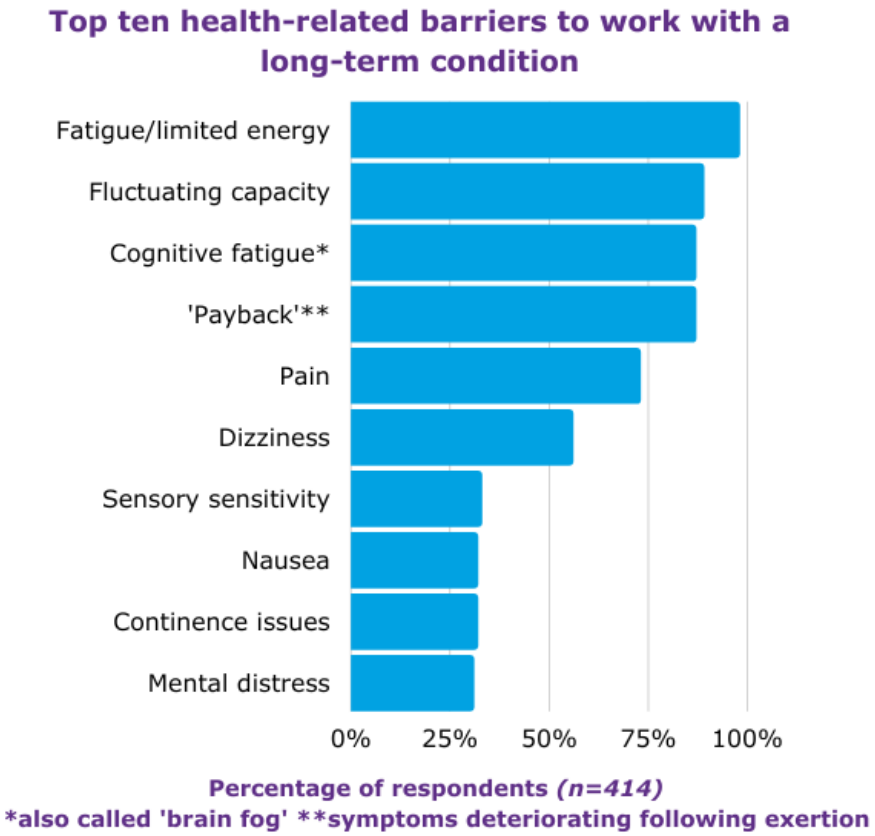


Figure 2. Graph titled 'Top ten health-related barriers to work with a long-term condition'. Please see chart description below.

Figure 2. Chart Description:

Bar chart showing the top ten health-related barriers to work reported by 414 respondents with energy-limiting conditions. Respondents were able to make multiple selections. Fatigue or limited energy was selected by 98% of respondents. Fluctuating capacity selected by 89%; cognitive fatigue, also known as 'brain fog' by 87%; 'pay back' aka symptoms that deteriorate following exertion, by 87%; pain by 73%; dizziness by 56%; sensory sensitivity by 33%; nausea by 32%; continence issues by 32%; mental distress by 31%.

These findings on illness-related barriers to work are crucial for understanding the relationship between work and health. They indicate that the lived experience of an ELC goes far beyond the surface notion of 'fatigue' as a subjective sensation of tiredness. The impact of cognitive fatigue and dysfunction on everyday work-related tasks like reading, communicating and concentration span show that an ELC not only limits capacity for jobs requiring physical exertion, but also many jobs in the knowledge economy. The fact that the pattern of many systemic diseases involves fluctuating symptoms and a varying capacity for work, often unpredictably, also forms a key barrier to many job roles. In a similar way, 'payback' (in some conditions known as post-exertional malaise, the negative consequences of attempting to 'push' through fatigue and ending up with exacerbated symptoms as a result) was also selected as a key barrier.

As our respondents testified, the consequences of a line manager not understanding the experiential nature of ELCs can be very damaging:

"In a previous role, an admin role, my line manager was horrendous and did not understand my illness and the fluctuations that can occur on a day-to-day basis. She was unwilling to flex in any aspect of my role be that working hours or location and felt that work could only be completed in the office environment".

In fact, when asked the reason for leaving their previous employment (or if they are employed, but want to leave), **48% of respondents selected that working in their previous job made their health deteriorate**. This demonstrates that pushing through symptoms of fatigue with an ELC is not a viable strategy for moving into, or remaining in, work. It also highlights the importance of raising awareness and training line managers on the experience of ELCs and other long-term and invisible health conditions.

Psychosocial and structural barriers to work

Our work with Astriid candidates suggests there are common challenges, or barriers, faced by people who are thinking about working or seeking work. These challenges include, but are not limited to, physical symptoms alone.

We asked respondents about barriers they face that could be addressed by the bespoke support services offered by Astriid. The most popular selections were *"I'm uncertain about what type or amount of work I could safely manage with my health condition"* (66%) and *"lack of confidence around access needs, rights, self-advocacy"* (49%).

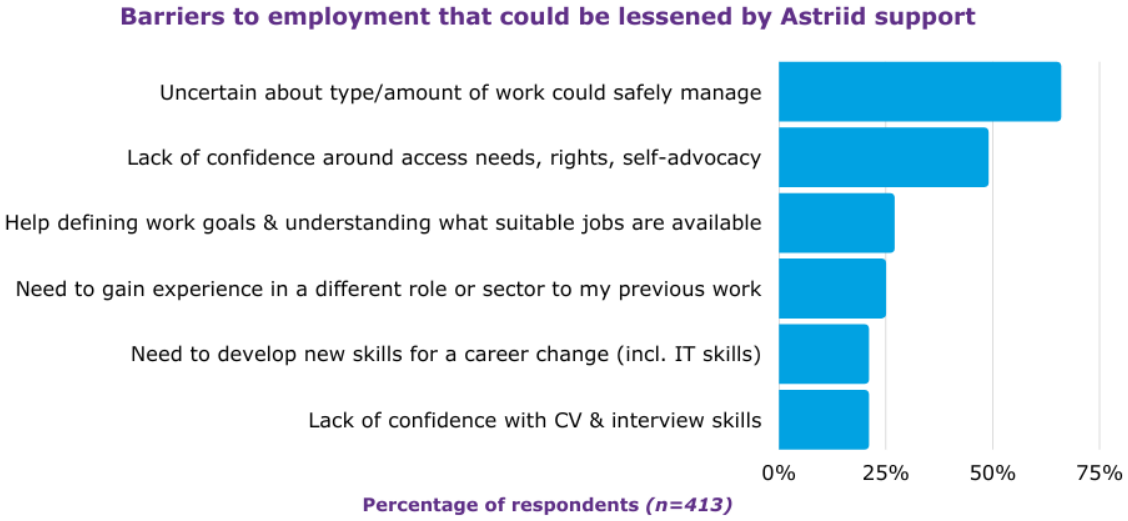


Figure 3. Graph titled 'Barriers to employment that could be lessened by Astriid support'. Please see chart description below.

Figure 3. Chart Description:

Bar chart showing psychosocial barriers to work reported by 413 respondents with energy-limiting conditions. These barriers were identified as those that could be lessened by Astriid support services. Respondents were able to make multiple selections. The barrier "I'm uncertain about what type or amount of work I could safely manage with my health condition" was selected by 66% of respondents. 49% selected "lack of confidence around access needs, rights, self-advocacy". 27% selected "I need help defining my work goals and understanding what suitable jobs are available". 25% selected "I need to gain experience in a different role or sector to my previous work". 21% selected "I need to develop new skills for a career change (can include IT skills)". 21% selected "Lack of confidence with CV and interview skills".

In our work with candidates, we are also aware of additional barriers that may be linked to a need for structural change or require other more holistic support services. We asked respondents how significant these were in preventing them from seeking or taking up employment even though they may have a desire to work.

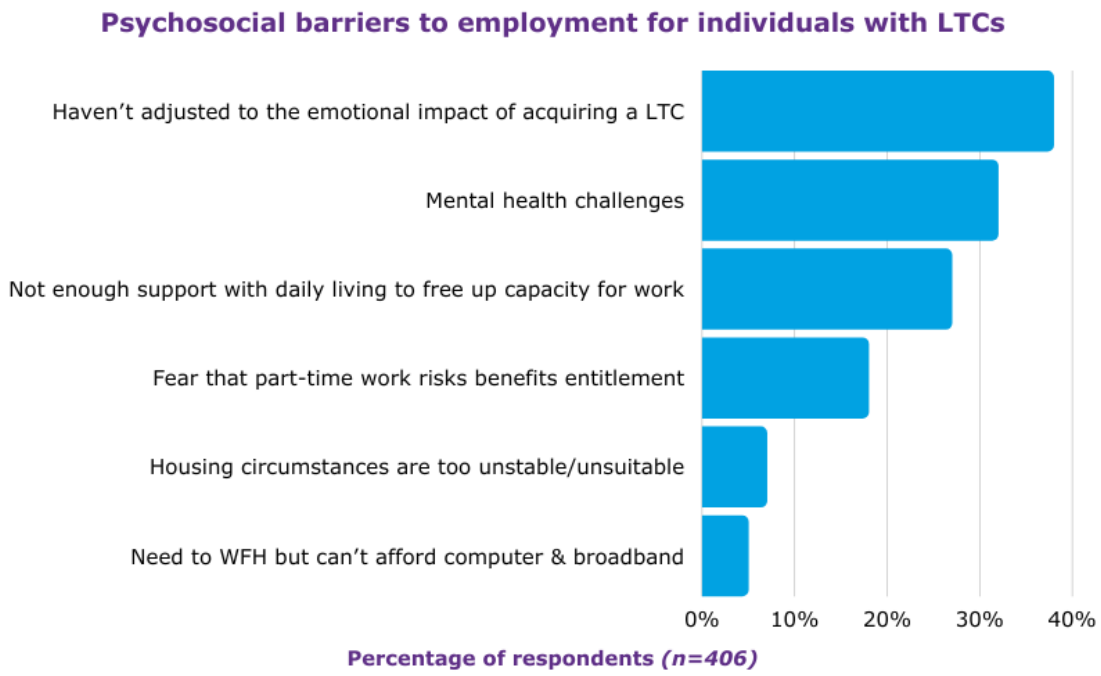


Figure 4. Graph titled 'Psychosocial barriers to employment for individuals with LTCs'. Please see chart description below.

Figure 4. Chart Description:

Bar chart showing wider psychosocial and structural barriers to work reported by 406 respondents with energy-limiting conditions. Respondents were able to make multiple selections. The barrier "I haven't adjusted to the emotional impact or loss of acquiring a long-term health condition" was selected by 38% of respondents. 32% selected "mental health challenges". 27% selected "I don't have enough care or support with daily living and household management to free up capacity for work". 18% selected "I fear that trying out part-time or project work would put my benefits entitlement as risk". 7% selected "my housing circumstances are too unstable or unsuitable". 5% selected "I need to work from home but can't afford a computer and broadband connection".

38% of respondents selected that they hadn't adjusted to the emotional impact of acquiring a LTC and 32% said they face mental health challenges. This evidences a crucial need for confidence building and job coaching services for this group that are informed by an understanding of the trauma of developing a LTC and focused on rebuilding a new professional identify. It also demonstrates the need for better mental health support services for those with LTCs, to help with access to work.

There was also an open-ended response ('other') option for this question. Socio-economic circumstances living conditions and transport restrictions were common themes.

"Transport from a rural town is almost impossible and exhausting as I cannot safely drive."

Other barriers that appeared consisted of managing regular medical appointments around work.

"The amount of time needed to manage my own health, in terms of symptom management, preparing for and attending appointments, managing appointments... it takes up so much of my life!"

Respondents were also concerned about their work history and reputation:

"I worry about the effects of my failed work attempts on my confidence, my reputation and my ability to gain employer recommendations".

"I fear my age and work history are a barrier to any meaningful employment."

These responses evidence how organisations like Astriid can meaningfully improve access to work for people with LTCs. This can be achieved in a number of ways, including confidence-building and exploring the type and frequency of work which would be most suitable and accessible. However, there are significant barriers which require wider, more structural change and improved access to other support such as social care support and mental health services.

How can employment support services help address the barriers?

We asked survey respondents what forms of employment support would be helpful, as well as what would help to widen the employment opportunities available to them.

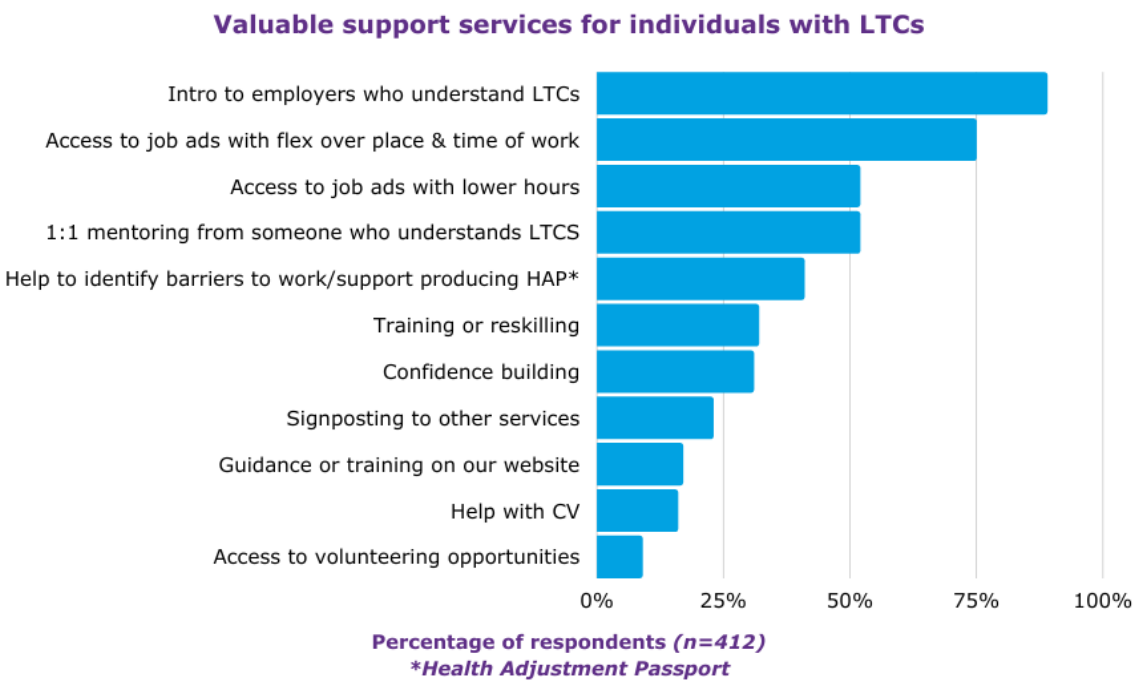


Figure 5. Graph titled 'Valuable support services for individuals with LTCs'. Please see chart description below.

Figure 5. Chart Description:

Bar chart showing what support services for accessing work are valuable for 412 respondents with energy-limiting conditions. Respondents were able to make multiple selections. "Introduction to employers who understand long-term conditions and disability" was selected by 89% respondents. 75% selected "access to job ads have more flexibility over place and time of work". 52% selected "access to job ads with lower hours". 52% selected "1:1 support or mentoring from someone who understands long-term conditions". 41% selected "help to identify your barriers to working and/or support with producing a Health Adjustments Passport". 32% selected "training or reskilling". 31% selected "confidence building". 23% selected "signposting to other services". 16% selected "help with CV". 9% selected "access to volunteering opportunities".

The most popular responses were an "*introduction to employers who understand LTCs and disability"* (89%) and "*access to job ads that have more flexibility over place and time of work"* (75%). This demonstrates the value to our beneficiaries of Astriid's core mission of engaging with employers, brokering job opportunities and matching suitable candidates with available roles. The data also highlight the importance of employers who are willing to look beyond conventional ways of working and embed flexibility into job design and recruitment practices.

We asked an additional question on what support these individuals would find most desirable, based on services Astriid has considered implementing.

71% of respondents selected *"support with managing health and wellbeing in work"*. This option was highly selected and corresponds with the need for on-going coaching and support around health management, not only through the recruitment phase but continuing once placed into a role. This corresponds with findings in Figure 1 showing that 'payback' or deterioration in health from over-exertion is one of the core features of ELCs that limit capacity for work, and that deterioration in health was the most likely reason for leaving previous employment. It also corresponds with uncertainty over hours and type of employment being a major barrier to seeking or taking up work. A programme that offers support with pacing limited energy and managing fluctuating symptoms in work that is informed by lived experience expertise should be available to all employees with long term physical health conditions.

Mental wellbeing is highly interlinked with the management of physical health conditions, and it is vital that workplace wellbeing services are accessible to, and attuned to, the needs of those who live with them.

43% selected that they would value *"**peer support** e.g. a buddy system or access to a community forum to discuss working with a long-term condition*".

39% selected that they would value *"**benefits advice** around part-time work".* This finding relates to the socio-economic barriers of accessing work that was highlighted in the psychosocial barrier response.

How can employers remove barriers to work for people with ELCs?

"My employer is very flexible as to when in the day I work, as long as I meet my hours at the end of the week. I've even been trained for new roles fully remotely."

Following on from previous sections, our data shows that widening job opportunities for people with ELCs requires employers to challenge and think creatively about the way that work is traditionally organised. This section is about workplace adjustments to support people with ELCs, but also suggests that jobs need to be inclusive at the point of design and recruitment.

Working styles

We listed various different types of flexible working, and asked respondents which working styles would help them to access work.

Working from home	**84%**
Flexible start & finish times	**81%**
Flexibility to determine my working hours within any given week	**75%**
Flexibility to take long breaks during the working day and defer work to later in the day/evening	**71%**
Part-time work	**70%**
Flexibility to spread your working hours across multiple weeks rather than within one working week	**62%**
Extra time off for assessment/treatment/rehabilitation (also known as Disability Leave)	**59%**
Hybrid working	**44%**

Table 1. Types of flexible working sought by respondents with ELCs

These findings demonstrate just how important remote and flexible styles of working are for people with LTCs to access work. Different types of flexibility may work for different people. **The most popular type of flexible working was "flexible start and finish times"**. However, more uncommon styles were also popular, including the ability to take longer breaks during the day and defer to later on, and the ability to determine working hours in any given week.

"I was given regular support with workplace adjustments. These included being able to work from home when I needed to and managing my hours with the flexibility I required to manage my energy levels. This support enabled me to be able to work full time in a job I love and manage my condition whilst working."

"I am currently in a team where my line manager fully understands the impact that my illness can have on my day to day 'hours' and how this does not define my ability to perform whilst having a 'good' day.

Hours

Although 17% of respondents stated they could work full-time, **68% selected that they required part-time hours.** The findings consisted of a wide range of hours, illustrating the variability in capacity amongst individuals with LTCs.

"Having later start and finish times helped manage my symptoms."

"My boss has been so understanding after I acquired my long-term condition a few months into starting my role... I have flexibility around start and finish times and rest periods during the working day."

Flexible working and ELCs

The striking popularity of flexible working styles among survey respondents with ELCs is in keeping with the illness-related barriers reported in Figure 1. Working from home and working reduced hours are both ways of accommodating fatigue and limited energy. Part time work allows people with ELCs to pace their work-related activities and allocate the energy they need to managing medical appointments, domestic tasks and family and leisure activities outside of work. Working from home preserves energy that is otherwise lost in commuting and in navigating the additional challenges of an office environment, e.g., increased noise and light stimuli while working or the exertion of unplanned communication with others. Flexibility of hours and worktime control, whether across the day, week or months, are essential to managing a fluctuating condition.

Flexible working and reasonable adjustments

The findings in Table 1 suggest that flexibility in hours or location of work are the main form of workplace adjustment sought by workers with ELCs. Traditionally, the understanding of 'reasonable adjustments' for disabled workers has centred on adaptations to premises, assistive technology or adaptive equipment. Our survey shows that the kinds of adjustments that confer greater autonomy over the pace and schedule of work are equally important when considering the inclusion of disabled workers.

Table 2 shows the categories that respondents' other access needs fell under. Providing a safe and accessible working environment was the most popular selection. This finding emphasises the importance of a suitable working space, with many workers with ELCs preferring remote work, as individuals are likely have more control over their workspace, can access quiet spaces for breaks, and have proximal and comfortable access to toilet facilities.

Policies and procedures were another popular selection. This included accommodations like providing interview questions in advance: this allows for a more even playing field for people with ELCs who experience cognitive fatigue. As we know this cognitive fatigue is a significant barrier to work and can impact thought processes in real time (likely even more so under the pressure of a job interview) and so allowing more time for people with ELCs to prepare would avoid them being disadvantaged at this stage, and so a helpful adjustment for many.

Providing a safe and accessible working environment (accommodations such as access to a quiet space; proximity to toilet facilities; ergonomic furniture; specialist IT software)	**75%**
Policies and procedures (accommodations such as providing interview questions in advance; allowing remote interviews)	**58%**
Communicating and interacting with people (accommodations such as changes to the format/length of meetings)	**54%**
Planning, organising and cognitive symptoms (accommodations such as advanced notice to change of routine)	**54%**
Sensory issues (accommodations such as flexible dress codes; allowing noise-cancelling headphones)	**43%**

Table 2. Access need categories reported by 362 respondents with ELCs.

Flexible working and inclusive recruitment

The popularity of flexible working as a disability adjustment mechanism corroborates the data from Table 1 about removing barriers to work.

Respondents were asked what would make them feel more able to share their access needs with an employer at the recruitment stage. 85% of respondents sought vacancies that mention flexible working provisions upfront in the job advertisement. This suggests that building flexibility into the design and advertisement of roles is a key determinant of whether respondents with ELCs will be encouraged to apply for a job.

Statements and information on disability inclusion from the employer were also highly selected. This, in combination with the earlier finding that the most valuable sought-after support service for individuals with ELCs is introduction to employers who understand LTCs, evidence just how important this is. The more employers are knowledgeable and understanding, the more confident people with ELCs can feel that that their essential access needs will be met.

Flexible working options stated in the job advert	**85%**
A statement from the employer about their commitment to disability inclusion in the recruitment information	**74%**

Disability and Inclusion information/policy prominent on company website	**70%**
A job advert that invited me to state my access needs at application stage	**53%**
An invitation from the employer to state my access needs at interview stage	**47%**

Table 3. Support that would help respondents with ELCs (n=410) more able to communicate Access Needs to an employer at the recruitment stage.

In conclusion, the findings throughout this report make a compelling case for flexible working as the key mechanism by which employers can boost both recruitment and retention of a diverse talent pool. In doing so, they can also ensure g that the significant proportion of the workforce who are already managing a long-term condition are empowered to perform at their best.

Conclusion

For far too long, the world of work has excluded talented individuals with Energy Limiting Conditions. This population has a wealth of skills and lived experience that can enrich a workforce, and yet many are never given the chance to thrive to their fullest potential. This report has highlighted the practical barriers that exist at present, and the adjustments that can help to overcome these barriers and level the playing field.

Astriid is uniquely positioned to support individuals who wish to find and remain in work alongside managing a long-term condition, and also employers who wish to diversify their workforce and bring about meaningful inclusion. We are experts by experience in working with Energy Limiting Conditions, but the increasing scale and urgency of this issue mean we are now calling on broader forces to step up and help us finally shape an employment landscape that's truly disability-inclusive.

Recommendations

The challenge of reconnecting people with long term conditions with meaningful work is one that must be shared by government, employment support providers and businesses alike.

Recommendations to government

We direct these recommendations to policy makers within the Department for Work and Pensions and the Department for Business, Energy and Industrial Strategy.

Specialist employment support services

Government should commission and fund specialist disability employment services for people with long term conditions that are informed by knowledge of ELCs.

Incentivising flexible job design

The government should explore all possible levers that encourage and support businesses to integrate people with LTCs into their workforce by designing more flexible and part time roles.

Flexible working by default

As a simple extension to the Employment Relations Bill, the government should require employers to include all possible flexible working options in job adverts. This will mean people with LTCs will know if a job works for them before they apply and underlines an employer's commitment to make flexible working work for everyone.

Research on work and health

In addressing the challenge of health-related economic inactivity, government should fund additional research on the interaction between work and health in determining what we mean by ‘good work’. This research must take account of the lived experience of disabled people, especially those with ELCs.

Improving disability employment data collection

Very little is known about the experience of people with energy limiting conditions because impairment categories across key surveys, such as the Labour Force Survey, are ad hoc and outdated.

Government should standardise disability and impairment categories across policy departments. As a minimum, this should include ‘impairment of stamina, breathing, fatigue’ as recommended by the Office for National Statistics, or

ideally, adopt the category of Energy Limiting Conditions, as used and better understood by disabled people themselves.

Recommendations to employment support providers

The landscape of employment support for individuals with LTCs and disabilities is rapidly evolving, and this offers an opportunity to incorporate Astriid's proven strategies into broader service provision.

Services for jobseekers with long term conditions should be designed alongside lived experience experts and should include the following features:

- Employer engagement and job brokering
- Job matching
- Job design and development
- Coaching to rebuild professional identity and goals
- Coaching to build self-advocacy skills and identify reasonable adjustments and support needs
- On-going support to manage a LTC within work
- Internship and volunteering opportunities that allow safe experimentation with hours and types of work
- Advice on income security and welfare benefits for people taking on part-time work.

Recommendations to employers

We direct these recommendations to leaders in Human Resources, Talent Management, Recruitment, and Diversity, Equity and Inclusion positions.

Training

Employers should provide awareness raising and equality training on supporting people with ELCs for all line managers.

Workplace flexibility

Employers should ensure that autonomy to work flexibly, to reduce hours and to work from home is granted in professions where this is feasible. This should be accompanied by regular contact with an individual's manager and colleagues, and realistic performance targets.

Recruitment

Flexible working provisions should be clearly stated in job advertisements to attract candidates with LTCs. This also benefits people from other marginalised groups, such as those with caring responsibilities and older workers.

Workforce planning, job design and internships

In order to attract the widest possible talent pool, flexible, remote and part-time roles should be embedded into job design wherever possible, rather than seen as a privilege to be earned. In addition, employers should consider creating opportunities for jobseekers to experiment with building their hours of work capability in a safe environment, for example through internships for those returning to the workplace following prolonged sickness absence.

Sickness absence management

Policies and processes for sickness absence management must be informed by lived experience knowledge of long term and energy limiting conditions, as well as healthcare professionals. Return to work plans must be personalised and created in partnership with the employee.

Diversity, Equity and Inclusion strategy

Long term conditions and energy limiting conditions must be included in every organisation's Diversity, Equity and Inclusion strategy, alongside other groups in the disability spectrum. This may extend to ensuring representation of ELCs in employee resource groups, in disability workforce data and reporting, in creating workplace adjustment passports, and more.

Appendix

Demographic data

	Number	Percentage
Gender		
Woman	369	89%
Man	25	6%
Non-binary	13	3%
Prefer not to say	5	1%
Genderfluid	1	0%
Age		
Under 18	0	0%
18-24	23	6%
25-34	98	24%
35-44	134	32%
45-54	111	27%
55-64	37	9%
Over 65	10	2%
Location		
England	354	88%
Scotland	31	8%
Wales	14	3%
Northern Ireland	5	1%
Ethnicity		
White	374	91%
Multiple/mixed ethnic group	16	4%
Asian/British Asian	8	2%
Black/African/Caribbean/Black British	3	1%
Prefer not to say	6	1%
Other ethnic group	6	1%
Gypsy, Roma, or Traveller	0	0%
Sexuality		
Straight or Heterosexual	312	76%
Bisexual	46	11%
Prefer not to say	26	6%
Gay or Lesbian	14	3%
Pansexual	6	1%
Asexual	3	1%
Queer	2	1%